

Disease Registry Issue Brief

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Chronic diseases, including heart disease, cancer, and diabetes, account for seven out of every 10 deaths and affect the quality of life for tens of thousands of Iowans. In 2007, chronic diseases accounted for 68% of all deaths in Iowa. A systematic and comprehensive approach to caring for patients with chronic diseases has been shown to improve the quality of chronic care delivery.

A disease registry can be an effective tool for providing this systematic and comprehensive care, and provides an introduction for many providers about how to effectively integrate and use health information technology in care settings. It is a cornerstone to effectively implement the medical home model and is crucial in the management of patients with chronic diseases. When using a disease registry, providers are able to track their patients individually and by population subset, which allows them to provide proactive care and treatment to individual patients or groups of similar patients.

Iowa's Health Care Reform legislation, [House File 2539](#), has tasked the Iowa Department of Public Health (IDPH) with coordinating the activities of several key advisory councils charged with making recommendations to improve the health of Iowans. This issue brief on disease registries was collaboratively developed by Iowa's Prevention and Chronic Care Management Advisory Council, Medical Home System Advisory Council, and Electronic Health Information Advisory Council. The issue brief is targeted toward providers, payers, policy makers, and other stakeholders to summarize the definition of a disease registry and describes how registries tools interrelate with electronic health records. The issue brief also provides improvement strategies and recommendations for promoting clinic-based and population-based registries to improve quality of care delivery.

Definition of a Disease Registry

A disease registry is a database that contains information about people diagnosed with specific types of diseases. The registry collects information that can be used for capturing, managing, and organizing specific information for a population of patients. Disease registries are either clinical-based or population-based.

Clinic-Based Registry

A clinical-based disease registry contains data on patients with a specific type of disease diagnosed and treated at a practice, which allows care team members to proactively manage patients with chronic diseases.

Population-Based Registry

A population-based disease registry contains and tracks records for people diagnosed with a specific type of disease who reside within a defined geographic region (i.e., a community, city, or statewide).

Benefits of a Registry

A disease registry is a powerful tool that can drive significant practice change and improve the health of the patients being served. They offer the provider, patient, and community a variety of benefits. Disease registries:

- enable the provider to ensure that all their patients are getting proper care
- track the progress of high-risk patients
- identify the need for follow-up services
- increase quality of care and improve patient outcomes
- empower patients to take an active role in their treatment
- coordinate care and identify gaps
- increase public awareness and prevent chronic diseases
- support the Chronic Care Model and Medical Home Model
- incorporate consensus guidelines for disease management
- determine best practices and support evidence-based care

Considerations

Iowa should carefully weigh the following factors when developing a statewide chronic disease registry:

- ability to interface with Electronic Health Records (EHRs) - pending legislation from the U.S. Department of Health and Human Services will likely require registry functionality within EHR systems as part of the EHR certification process
- incentives for providers to purchase and use a registry tool
- funding for a statewide registry (e.g., costs to develop interoperability standards for vocabularies, data elements, datasets and an interface with the statewide health information exchange; and the resources to analyze the information and make actionable recommendations)
- where the statewide registry will be housed and managed
- sustainability issues maintenance and adapting to future needs)
- legal issues of confidentiality and who has access to the data
- communication and outreach to educate providers about registries and EHRs

Electronic Health Records and Registry Tools

Nationally and throughout Iowa, providers are being encouraged to adopt electronic health records (EHR). EHRs are used to store patient information electronically, rather than relying on traditional paper records. EHRs are necessary to enable the electronic exchange of information (e.g., through a secure statewide health information exchange). EHRs can support improvements in quality of care, patient safety, and care coordination. Registry tools generally manage a much smaller amount of patient information than an EHR and may be easier to use when managing information for a targeted group of patients. Some EHRs have a registry function and for those that do not, software can be used to connect registries and EHRs. This provides the benefits of EHRs and registries while eliminating the need to enter data more than once (e.g., in the EHR and in the registry).

“A physician who opens the chart may see the blood sugar is up. But that doesn’t tell the clinician that out of 200 patients with diabetes, 10 are out of control.”

- ACT report.

Iowa Legislative Health Care Coverage Commission- Diabetes Registry Recommendation

The Legislative Health Care Coverage Commission was created by the Iowa General Assembly in 2008 and began work in September 2009. The Commission is made up of 11 voting members, four legislators, and three department heads. The charge of the Commission is to submit recommendations to increase access to health care coverage to low income adults in Iowa. The Commission completed a progress report to the Iowa General Assembly which summarizes the Commission's activities from September through December 2009. The report with recommendations can be found here: <http://www.legis.state.ia.us/lsadocs/IntReport/2010/IPAMV000.PDF>.

One of the Commission's recommendations is that Iowa should develop a **statewide diabetes registry** to improve care for patients with diabetes. To improve the care of diabetic patients and begin the process leading to upcoming Medicaid expansion, the state should set up a diabetes registry with the assistance of Iowa's Community Health Centers and free medical clinics, which in exchange for data and lab tests will provide a basic combination of medications, including antihypertensives, cholesterol-lowering agents, and diabetes medications.

Example of a Disease Registry Data Report

Below is an example of a monthly report from Mercy West Medical Clinic's disease registry. The Clinic is able to run this same report for each of its providers so that the provider knows exactly how their patient population is doing.

All Population Diabetes Data: 1/1/08-12/31/08									
Clinic	Beaverdale	Campus	East FP	Jefferson	North FP	Panora	South	Urbandale	West FP
Total Patients	760	597	832	592	1113	80	890	840	997
Process goals:									
HgA1c last 12 mo.	89.7%	93.1%	90.5%	75.0%	93.6%	95.0%	93.4%	88.3%	85.0%
LDL last 12 mo.	85.0%	87.9%	85.1%	43.0%	86.4%	92.5%	88.1%	81.4%	82.2%
Microalbum last 12 mo.	74.7%	78.2%	72.1%	37.3%	76.6%	85.0%	74.6%	77.4%	68.5%
Eye Exam last 12 mo.	41.7%	31.7%	44.4%	21.6%	48.4%	40.0%	37.9%	48.8%	35.1%
Outcome goals: Not done in the last 12 mo. Indicates a failure									
% HgA1c ≤ 8.0	76.6%	69.2%	76.3%	61.7%	77.5%	70.0%	79.0%	78.0%	72.0%
% HgA1c ≤ 7.0	59.1%	50.1%	61.4%	45.6%	56.1%	47.5%	58.9%	59.2%	50.6%
% LDL < 130	72.5%	70.4%	69.8%	37.0%	78.0%	73.8%	74.2%	74.4%	73.9%
% LDL < 100	52.5%	51.3%	50.8%	27.2%	59.2%	52.5%	58.2%	62.5%	55.4%
% BP < 140/80	56.7%	62.3%	66.8%	31.0%	49.4%	63.8%	52.4%	64.5%	55.5%
All Population HTN Data: 1/1/08-12/31/08									
Clinic	Beaverdale	Campus	East FP	Jefferson	North FP	Panora	South	Urbandale	West FP
Total Patients	1852	995	839	417	3311	46	733	813	2455

Iowa Registries in Action

Chronic Care Model and the Development of the Health Disparities Collaboratives

The HRSA Health Disparities Collaboratives (HDC) was developed to transform primary health care practices to improve the health care provided to everyone and to eliminate health disparities. HRSA worked with these organizations and the Institute for Healthcare Improvement (IHI) to develop the evidence-based systems of improvement within the HRSA Health Disparities Collaboratives. Use of a registry has been a key component of the HDC since its inception to facilitate clinical decision support and track improvements in health outcomes. The value of the registry was recognized then and provided to health centers participating in the HDC long before these systems were commonly used in the private sector. In 2007 most of the Iowa CHCs upgraded to the currently used population health management system now in use which added additional functionality, flexibility and less duplication in data entry.

Examples from the Community Health Centers in Iowa

There are 14 Community Health Centers (CHCs) in Iowa serving nearly 138,000 individuals. Eleven of the CHCs use the same population health management system and two other registry systems are in place in an additional two CHCs. The CHCs believe it is important to make the distinction between a population health management system and a registry, which can have multiple definitions and connotations. Below is a brief history of the chronic care model and health disparities collaboratives as well as examples of how a population health management system can improve care for patients and allow for better access to critical data for expanded clinical decision-making.

Community Health Center Tobacco Cessation Program

IA/NEPCA received a grant from the Iowa Department of Public Health in 2007 to administer a free tobacco cessation program in 13 of the CHCs in Iowa. The program allows uninsured, underserved, and low-income Iowans access to free counseling and medications and the centers are currently in third year of offering the program. As part of the program, the CHCs set up a tobacco cessation tracking type in their population health management system, which allows each center to track and report on the demographics of patients served through the program as well as the services provided to patients on a monthly, quarterly, and annual basis. Using the management system, centers were also able to look at the prevalence of other chronic diseases among their patients enrolled in the tobacco cessation program.

Iowa Registries in Action (Cont.)

Using Data from a Population Health Management System

As an example of how data from a population health management system can be turned into actual management of population health, a CHC in Iowa took a look at patients in its system who had “no HgA1C recorded in the last year, but had at least two visits.” This created a list of patients for whom it would seem did not receive optimum care. By investigating each patient on this list, the center was able to determine that some of these patients were not diabetic, indicating there had been a past problem with the data capture process, which was easily corrected by removing these patients from the population health management system. A second group had HgA1C results in the chart, but not in the management system, thus identifying a process problem with data capture within the center that needed to be fixed. And, a third group indeed did not have a HgA1C done in the last year, but could then be contacted to come into the center to receive an up-to-date HgA1C. This last group also revealed a fourth subgroup whose recorded HgA1Cs had been consistently low, suggesting that providers were choosing not to run HgA1C testing as frequently as guidelines suggest, knowing that these patients were well-controlled. This last subgroup also suggested that using a clinical quality marker such as, “two HgA1Cs, collected at least six months apart,” may not always tell the full story about the adequacy of care being provided.

Wellmark Diabetes Grant

In 2006, the Center for Value in Healthcare (CVH), an affiliate of the Iowa/Nebraska Primary Care Association (IA/NEPCA) received a Wellmark Diabetes Grant. Among other goals, the grant proposed to measure a diabetic health outcome, average HgA1c by race and potential cost savings measures. The HgA1c is a test that measures a person’s average blood sugar control over a certain amount of time, usually 2 to 3 months. The goal for people with Diabetes is a level less than 7%. Iowa’s CHCs participated in the project and were able to pinpoint their 5,500 diabetic patients through their population health management system. The participating CHCs were able to show that there was a drop in their diabetic patients’ HgA1c levels from an average level of 8.3 to 7.5 over the life of the project. This clinical data was also measured and collected by using the population health management system that is housed within IA/NEPCA, but is utilized by the local CHCs. The CHCs attributed their success in better managing their diabetic patients to providing a medical home for patients and using elements of the Chronic Care Model such as care teams and population health management systems.

CVH then used the financial tool IMPACT to measure cost savings over three years. By figuring the drop in the HgA1c levels, the IMPACT software was able to project substantial cost saving over three years of 3.6 million dollars to the health care system. These savings accrue directly to the payers of health care. For example, based on an average number of Wellmark patients served by the CHCs at the time, 8%, the savings to Wellmark would have been about \$293,000. For Medicaid, which was over 20% of the CHCs’ diabetic patients at the time, the savings would have been about \$750,000. This analysis did not account for additional savings for the reduction of other health outcomes that generally occur with the proper maintenance of HgA1c levels such as cholesterol and blood pressure levels. It should also be noted that the results of this project are even more impressive when one accounts for the large uninsured population, nearly 40% that the Iowa CHCs served during the grant-funded period.

“The registry is the cornerstone of chronic disease management and the Chronic Care Model.”

- ACT report

Iowa Registries in Action (Cont.)

Mercy Clinics and the Chronic Care Model

The Mercy Clinics had incorporated portions of the clinical information component of the Chronic Care Model as early as 1998, but adopted the entire model in 2002. “We are operating this model in four of our clinics, beginning with a focus on diabetic patients, and then expanding to those with hypertension,” explains David Swieskowski, M.D., Vice President of Quality Improvement. “Each of our clinics is responsible for creating its own **populated data base**, and the work flow in caring for those patients is a little different in each setting.” Within each setting, there are clinic-tailored processes that relate to all six elements, such as decision support (standing orders and best practice guidelines), self-management support (as practiced through the 5 –A’s of assess, assist, arrange, advise, agree), and making local community resources available to patients and families. Dr. Swieskowski, in his administrative role, sends system level monthly reports to his physicians to provide feedback on pre-established clinical indicators. “It is important that our health care team knows how they are doing in terms of moving the indicators in positive directions, and how their office practice compares to their peers,” states Dr. Swieskowski. As an added incentive, these clinics are part of a “Pay for Performance” pilot project of Wellmark Blue Cross Blue Shield. “We will be incented by Wellmark to keep our patient’s HbA1c. Dr. Swieskowski also values using a team-based approach to supporting patient care. Each health professional, be it a nurse, dietitian, or other, has a skill set and keeps up their knowledge according to their specialty. This takes pressure off the physician to be “up to date” with best practices in all areas. For more information visit <http://www.mercydesmoines.org/>.

Recommendations

- Iowa should promote clinical registries and a population-based chronic disease registry capable of measuring multiple health conditions or services. The registry tools should be integrated with EHRs and have ease of use and multiple applications for disease reporting and population management.
- Build the statewide chronic disease registry incrementally by selecting a small number of high priority diseases initially, and accommodating additional diseases in the future.
- Pursue national standards for chronic disease reporting measures such as National Committee for Quality Assurance (NCQA) or Physician Quality Reporting Initiative (PQRI)
- Determine best practices for use of population based information obtained from the registry that will encourage prevention, intervention, and evaluation of chronic diseases.